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TITLE: Cognitive-Affective Predictors of the Uptake of, and  
Sustained Adherence to, Lymphedema Symptom Minimization  
Practices in Breast Cancer Survivors

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| 13. ABSTRACT (Maximum 200 Words)<br>Approximately 20-30% of women develop lymphedema (LE) following breast cancer treatment; this condition has been associated with psychological distress and diminished quality of life. Effective symptom management requires that women not only recognize early signs of this condition, but that they uptake and maintain precautionary practices over their lifetime. Yet, the limited data available indicate that knowledge and use of symptom minimization precautions are poor, particularly over time. Unfortunately, little is known about how breast cancer survivors perceive their LE risk status, and the cognitive-affective factors that promote the uptake of, and adherence to, LE symptom minimization precautions. Further, the moderating role of individual differences in attentional style has not been explored. Guided by the Cognitive-Social Health Information Processing (C-SHIP) model, we will conduct a longitudinal study, to assess the barriers and facilitators associated with knowledge about, and adherence to, LE symptom-minimization practices among breast cancer survivors currently unaffected by LE. We will explore the mediating role of cognitive-affective variables, and the moderating role of attentional style, on knowledge, uptake and adherence over time. Toward this end, we will survey levels of knowledge, and the practice of symptom minimization precautions at baseline, and again at 6-, and 12-month follow-up. |   |  |   |  |
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## INTRODUCTION

Improvements in breast cancer treatments have greatly reduced mortality rates (Petrek 2000; Passik 1998; Erickson, 2001; Tasmuth 1996). Consequently, it has been recognized that greater attention needs to be given to survivorship issues, such as the management of post-treatment side effects such as lymphedema (LE), that compromise physical and psychological functioning and quality of life (Passik & McDonald 1998; Erickson, Pearson, et al., 2001; Brenes, Mihalko, et al., 2001). Yet, little is currently known about women's knowledge and practice of precautionary behaviors to prevent or lessen the impact of this condition (Coward, 1999; Clark, Wasilewska, et al., 1997). Guided by the Cognitive-Social Health Information Processing (C-SHIP) model (Miller, Shoda, et al., 1996; Miller & Rodolitz, 1996; Miller & Diefenbach, 1998), the overarching objective of the present study is to explore the cognitive-affective factors associated with knowledge about LE symptom-minimization practices, their initiation, and the sustained maintenance of these practices among breast cancer survivors currently unaffected by LE.

The specific aims of this project are as follows:

**Aim 1:** To delineate the underlying cognitive-affective mediating mechanisms (i.e., women's self-construals, expectancies, values and goals, affects, and self-regulatory strategies) that facilitate or undermine the uptake of LE symptom-minimization practices, and their sustained adherence over time. These cognitive-affective patterns will be assessed and related to levels of knowledge and the practice of symptom minimization precautions, at three points in time: baseline (within 6 weeks post-surgery), and again at 6- and 12-month follow-up post-baseline. It is hypothesized that greater LE-knowledge, greater intent to establish practices and/or adhere to existing practices, as well as greater uptake of recommendations and sustained adherence will be associated with heightened risk perceptions; greater self-efficacy, greater perceived benefits of, and fewer barriers to, enacting symptom minimization practices; lower LE-related distress; and greater ability to perform self-regulatory strategies.

**Aim 2:** To assess the moderating role of stable differences in the individual's cognitive-emotional profile or "psychological signature" on the uptake and adherence of LE symptom minimization practices and personalized cancer threats and challenges, over time (Miller, 1995). Specifically, it is predicted that high monitors (who attend to, focus on, and personalize cancer threats) will show greater knowledge, uptake, and adherence than low monitors (who distract from and downplay the significance of cancer threats and challenges).

To accomplish these objectives, we are conducting a longitudinal study of LE symptom-free women who are in remission following sentinel or axillary node surgery for early-stage (Stages I-II), primary breast cancer ( $N = 178$ ). A Nurse Educator from one of the two FCCC recruitment sites, the Breast Evaluation Clinic at FCCC campus or FCCC's Bryn Mawr satellite location, will make potential participants aware of the study through the provision of a leaflet describing involvement in the study upon registration for their clinic appointment. A member of the FCCC research team will review FCCC's

electronic medical records, the Health Information Management System (HIMS), to identify clinic patients and to determine patient eligibility (i.e., diagnosis, surgery status). The research staff will then contact eligible patients by telephone to describe the study, solicit participation and obtain verbal consent for participation. Eligible, consenting participants will complete psychosocial measures and a written informed consent at their next post-surgery follow-up appointment, usually within two weeks of initial contact and consent. Upon completion of the baseline questionnaire, each participant will be given a copy of the American Cancer Society Lymphedema booklet containing hand and arm care following surgery or radiation therapy for breast cancer and the recommended precautionary actions that they can follow will be briefly summarized verbally. Relevant psychosocial and behavioral variables will be reassessed by telephone at each of the follow-ups, 6- and 12-months post-baseline. Participants who experience a breast cancer recurrence will be excluded from follow-up and will be replaced in the study design.

## **BODY**

During year 1, the plan was to initiate Tasks 1 and 2 and complete Task 1, as outlined in our approved Statement of Work.

The specific aims of Task 1 were:

- a. Modify provisional measures according to Institutional Review Board (Months 1-2)
- b. Establish Recruitment Procedures/  
Train Staff (Months 1-2)

Task 1 was accomplished according to schedule.

The aims of Task 2, to be initiated in year one and completed in year two, are as follows:

- a. Recruit Participants, Conduct Longitudinal Study (Months 2-21)
- b. Establish Database and Enter Data (Months 2-21)

An additional six months from the originally proposed recruitment initiation date were required to obtain final DoD approval for four main amendments to the originally submitted protocol, which were necessary to enhance recruitment and retention in the study. These amendments included:

1). Changes to the original consent form were made in October 2002 according to recommendations from the DoD Office of Regulatory Compliance and Quality Review. At this time a question was added to the questionnaire, which was inadvertently omitted, a cover sheet was added to the questionnaires, and project staff involvement was clarified and new staff were added.

2). To increase enrollment, we have added FCCC's Bryn Mawr office as an additional recruitment site. This was approved in December 2002. Also at this time the recruitment procedure was modified to accommodate HIPAA requirements regarding solicitation and protection of patient information at this offsite location. Specifically, the task of

identifying potential participants and describing the study to the participants became the responsibility of the clinic's Nurse Educator rather than the FCCC Health Educator. Staff allocation was also updated at this time.

3). In March 2003, approval was provided for changes to the format and appearance of the patient recruitment flyer in an effort to make it more visually appealing. In place of a sheet of paper containing study information text, we created a fully colored tri-fold brochure. In addition, the information provided in the brochure was modified slightly to make it clearer and easier to understand. The format and presentation of the study questionnaire was also modified to facilitate completion and reduce the time burden placed on participants. The actual content of the questionnaire was not altered but simply presented in a different manner.

4). Finally, in June 2003 Michelle Rodoletz, Ph.D, a licensed clinical psychologist in the Psychosocial and Behavioral Medicine Department of FCCC, was included as a contact person on the Informed Consent form and her phone number replaced the original phone number provided. In addition, due to staff changes, Melanie Glenn was listed as the new Project Manager taking the place of Lisa Brower. Lisa Brower's name was removed from all project-related materials upon approval of the amendment.

The need to obtain FCCC internal, as well as DoD external, approval of these amendments caused delay and hampered recruitment efforts in this report period. This situation was further complicated by changes in DoD personnel, which resulted in the loss of a primary contact for 2 months. However, we are now in the process of actively recruiting patients for participation to our full capability and have established, and will be able to maintain, momentum. In addition, a computer database has been developed and data entry is ongoing, which will facilitate tracking and reporting of results.

The aims of Task 3, also to be initiated in year 1 and completed in year 2 are as follows:

- a. Analyze Preliminary Data (baseline to 6-month follow-up) (Months 4-21)
- b. Annual Reports Prepared (Months 4-21)

To date, preliminary baseline data have been entered and descriptive statistics have been performed. Since January 8, 2003 a total of 300 patients have visited the Breast Evaluation Clinic at FCCC proper and the Bryn Mawr satellite location. Patient contact and study solicitation was initiated in February 2003 and the first baseline interview was completed in February 2003. Since January 2003, 66 of the 300 clinic patients (22%) have been identified as eligible for the study (i.e., early stage at diagnosis, LE symptom free, receiving treatment at FCCC's main location and/or Bryn Mawr). To date, of the 66 eligible women, our research team has successfully contacted 52 (79%) by using a maximum of 20 attempts to contact women by telephone. Attempts are still being made to contact the other 14 eligible women. Of the women contacted, 28 (54%) provided verbal consent to participate. Twenty-four of the women contacted (46%) declined participation with 12 women stating that they were "not interested" with no additional



explanation provided, 8 women citing non-study specific related factors (i.e., language/communication barriers, already participating in another research study, lack of transportation), 2 women reporting limitations in time, and 2 women citing emotional reasons (i.e., heightened anxiety). To date, 20 of the 28 consenting eligible participants have completed baseline data. Eight originally consenting eligible participants have attrited from the study (6 participants through passive attrition [i.e., not showing up; not returning telephone calls], 2 participants through active attrition [i.e., changing their minds about participation.]). Six-month follow-up questionnaires are scheduled to begin being distributed in late August 2003.

## **KEY RESEARCH ACCOMPLISHMENTS**

- Held weekly project staff meetings.
- Established procedures for recruitment at FCCC and FCCC Bryn Mawr offsite location and began recruiting participants from both sites in February 2003.
- 20 participants have completed baseline measures. The first participant accrued is scheduled for 6 month follow-up in late August 2003.
- Twice weekly, members of the research team access the FCCC electronic Health Information Management System (HIMS) to identify new patients attending the Breast Evaluation Clinic at either site. Approximately, 5-10 new potential participants are identified on a weekly basis. Potential participants are FCCC patients who are initiating their breast cancer treatment or women who have come to FCCC for an initial consultation or post-diagnosis/pre-treatment second opinion.
- Potentially eligible women are tracked on a regular basis weekly in HIMS until their full eligibility (i.e., cancer stage, post-surgery status, receiving treatment at FCCC) can be determined. Using HIMS, a subset of approximately 20 patients are systematically tracked for eligibility in the course of a typical week. Eligible patients are contacted by telephone to solicit participation in the study after their medical records indicate that they have completed their surgery.
- Established a database that corresponds to the entire questionnaire and entered all available baseline data.
- Developed a system using an Access database to track participant follow-up. After a participant completes the baseline survey they are entered into the Access database and monitored to coordinate their follow-up interview date.
- In an effort to enhance recruitment, plans are being developed to extend recruitment to breast cancer patients receiving care at two FCCC area network hospitals (i.e., Virtua Memorial Hospital of Burlington County and Virtua West Jersey).
- Further efforts to enhance enrollment include the extension of the inclusion criteria to solicit patients with Stage 111a disease since breast cancer treatment and symptoms pose similar issues for patient with Stage II and IIIa disease.
- Published 4 review papers that analyze literature on adherence and adjustment in breast cancer disease/risk context and integrated findings obtained with our guiding theoretical model.

- Cornfeld, M., Schnoll, R.A., Higman, S., Babb, J., Miller, S.M., Henigan-Peel, T., Balshem, A., Slater, E., Ross, E., Siemers, S., Montgomery, S., Malstrom, M., Hunt, P., Boyd, S. & Engstrom, P. (2002). Implementation of a comprehensive cancer control program at the worksite - Year one summary report. Journal of Occupational and Environmental Medicine, 44, 398-406.
- Miller, S.M. & Sherman, K.S. (in press). Cancer screening. In N. Anderson (Ed.) The Encyclopedia of Health and Behavior. CA: Sage Publications.
- Miller, S.M., Bowen, D. J., Campbell, M.K., Diefenbach, M.A., Gritz, E.R., Jacobsen, P.B., Stefanek, M., Fang, C.Y., Lazovich, D., Sherman, K.A., & Wang, C. (in press). Current research promises and challenges in behavioral oncology: Report from the American Society of Preventive Oncology Annual Meeting. Cancer Epidemiology, Biomarkers and Prevention.
- Sherman, K.S., Miller, S.M., & Sheinfeld-Gorin, S. (in press). Psychosocial determinants of participation in breast cancer risk counseling programs and screening regimens among African American women. In: Breast Cancer in African-American Women. NY: Susan G. Komen Foundation and African American National Advisory Committee.
- We are also preparing two volumes that will integrate our ongoing study with the larger field of behavior and oncology.
  - Miller, S.M., McDaniel, S., Rolland, J., & Feetham, S. (Eds.) Individuals, families, and the new genetics. New York: Norton Publications, in press.
  - Miller, S.M., Bowen, D., Croyle, R. & Rowland, J. (Eds.) Handbook of psychosocial approaches to cancer prevention. Washington, D.C.: American Psychological Association, in preparation.
- Dr. Miller presented as an invited keynote plenary speaker at the DoD-sponsored Era of Hope Breast Cancer Research Conference, as part of a plenary session on breast cancer prevention, Orlando, Florida, 2002.

## REPORTABLE OUTCOMES

## BACKGROUND CHARACTERISTICS OF STUDY PARTICIPANTS

To date, 20 participants have completed baseline measures. Sample characteristics from these preliminary data include: a mean age of 54 years (range 34-69 years), 80% Caucasian, 65% married or living with a partner, 90% have children, 40% have earned a college degree or higher, and 60% have an annual household income of \$45,000 or



greater. Approximately half the sample (52.6%) have been diagnosed with Stage 1 breast cancer, 21.1% with Stage 2 breast cancer, and 26.3% report not knowing whether their cancer stage at diagnosis was Stage 1 or Stage 2. With regard to treatment methods the overwhelming majority of the sample (85%) received multiple treatment methods (lumpectomy and lymph node dissection 42%; lumpectomy, mastectomy, and dissection 16%; lumpectomy, dissection and radiation .05%; mastectomy and dissection 11%; mastectomy, dissection, and chemotherapy 16%). 67% of the lymph node dissections were sentinel node and 33% were axillary node.

### **LYMPHEDEMA-RELATED KNOWLEDGE**

At baseline, LE-related knowledge was reasonably high, with 60% of the women answering the majority of questions (17 out of 19) correctly. All of the women (100%) were able to correctly identify that it is recommended to keep your LE affected arm very clean and well moisturized, to avoid exposure of your affected arm to the sun, and to try to avoid any trauma in the affected arm (bruising, cuts, sunburn or other burns, sports injuries, insect bites, cat scratches). However, despite the generally high level of LE knowledge, 40% of the women answered at least one quarter of the more detailed LE-related knowledge questions incorrectly. The questions most frequently answered incorrectly were related to LE-related symptoms ("An inflammation or infection in the affected arm is a sign of LE", 45% incorrect), its onset ("LE can ONLY occur within the first month following surgery for breast cancer", 25%), BRCA treatment risk-related factors ("Breast cancer treatment increases your chances of developing LE", 25%; "Women who have axillary node surgery followed by radiation therapy have a higher risk of developing LE", 25%), and frequently performed risk-related behaviors ("Avoid temperature changes when bathing or washing dishes", 25%; "Only use an electric razor to remove hair from under your arm", 25%).

### **ADHERENCE TO LYMPHEDEMA MINIMIZATION PRACTICES**

Using a dichotomous yes/no item format, preliminary baseline data show that adherence to certain LE-risk minimization strategies is high, especially those that entail more passive acceptance strategies. Specifically, 95% of the women are not cutting the cuticles of their affected arm (i.e., arm associated with the surgery); 95% are keeping their affected arm very clean and well moisturized; 90% are avoiding heavy lifting and carrying handbags with over the shoulder straps; 90% are avoiding tight jewelry around the affected fingers or arms; 85% are avoiding exposing the affected arm to the sun; and 80% of the women are currently avoiding blood pressure readings and injections on the affected arm. However, 65% of the sample are not currently using an electric razor to remove hair under their affected arm, 45% are not wearing gloves when doing housework or gardening, and 30% are not avoiding extreme temperature changes when bathing or washing dishes. These are three important, and rather routine, behaviors recommended to prevent LE that require more active strategies. Moreover, 35% report that they do not consult with the doctor if they have any slight increase of swelling in the affected arm, hand, fingers, or chest wall.

## **PSYCHOSOCIAL PROFILE OF STUDY PARTICIPANTS**

### **Attentional Style**

Mean scores for the Monitor-Blunter Style Scale (MBSS) are comparable to those found in related research (Mean monitoring score=8.05, SD=2.78; Mean blunting score=4.35, SD=2.30).

### **Risk Perceptions**

Overall, participants tended to underestimate their risk of developing LE. Specifically, when asked to rate their risk for developing LE on a 5 point Likert-type scale ranging from 1="much lower than average" to 5="much higher than average", 75% of the sample reported that they were at an average to much lower than average risk for developing LE, despite the fact that in all cases the lymph node surgery they received placed them at an increased risk in comparison to breast cancer patients who do not have lymph node dissection or radiation. Moreover, of the women sampled who had received axillary node dissection, a treatment associated with an even higher risk for LE than sentinel surgery, 67% reported that they had an average to below average risk for LE despite the higher risk for LE development associated with this type of surgery. The actual risk of developing LE following axillary lymph node dissection increases to 38% to 56% when adjuvant radiation is provided, however no participants to date have had this treatment combination.

### **Expectancies**

With respect to outcome related expectations, using a 5 point Likert-type scale ranging from 1="not at all" to 5="very much", a subset of women endorsed that LE is a serious condition (i.e., 30% "quite a bit"; 5% "very much"), that developing LE would interfere with their lives (i.e., 45% "quite a bit"; 20% "very much"), and that LE-related problems would last a long time (i.e., 30% "quite a bit"; 15% "very much"). A majority of the women endorsed a belief that there are measures they can take to prevent LE (i.e., 50% "quite a bit"; 25% "very much") and that practicing the recommended hand and arm procedures will minimize their chances of developing LE (i.e., 50% "quite a bit"; 35% "very much").

With regard to self-efficacy expectations, using the same Likert-type scale, a majority of the sample indicated that they did "not at all" believe that whether or not they developed LE was God's will (60%) or that the development of LE is just luck (60%), implying that they did not take a fatalistic view of LE development. A majority of the sample were certain that they can effectively adhere to recommended procedures to minimize LE risk (i.e., 35% "quite a bit"; 30% "very much") and that they will be regularly checking themselves for signs of LE (i.e., 35% "quite a bit"; 25% "very much"). The data indicate

that although a majority of the women have positive expectations regarding LE preventive actions and a belief in their ability to carry them out, there is a large subset of individuals for whom this may not be the case.

### **Distress**

As measured by the Revised Impact of Events Scale (RIES), participants reported low to low-moderate LE risk-related distress, as defined by the presence of intrusive and avoidant risk-related ideation (Mean intrusion scale score=5.21, SD=6.81; Mean avoidance scale score=7.42, SD=8.25).

Using a 5-point Likert-type scale ranging from 1="not at all" to 5="very much", women were asked to rate their LE-risk related affect. Overall, women reported low levels of risk-related affect. Specifically, a majority of women endorsed "not at all" or "a little bit" when asked if they were experiencing thoughts of LE that affected their mood or ability to perform daily activities (60% "not at all", 5% "a little bit"), or the experience of LE-risk related worry (25% "not at all", 55% "a little bit"), sadness/depression (25% "not at all", 45% "a little bit"), anxiety (15% "not at all", 50% "a little bit"), or anger (45% "not at all", 20% "a little bit"). However, despite this tendency to manage LE-risk related emotions, there is a subset of women for whom risk related affect was more present. For example, there is a group of women who endorse "somewhat" to "quite a bit" when asked if they have LE-related thoughts that have affected their mood (10% "somewhat", 25% "quite a bit") or daily activities (15% "somewhat", 10% "quite a bit"), or feel worried (15% "somewhat", 5% "quite a bit"), sad/depressed (20% "somewhat", 10% "quite a bit"), scared/anxious (25% "somewhat", 5% "quite a bit"), or angry (35% "somewhat") regarding their LE risk. Moreover, a number of women report that they are "somewhat" (30%) to "quite a bit" (5%) worried about knowing when to contact the doctor about any LE symptoms they experience.

### **Values and Goals**

Overall, women reported placing a large degree of value on their physical appearance and physical functioning. Using a 5-point Likert-scale ranging from "not at all" to "very much," the entire sample reported "functioning well" to be "quite a bit" (20%) to "very much" (80%) important to them. Similarly, the entire sample reported "feeling well" to be "quite a bit" (20%) to "very much" (80%) important to them. In addition, the majority of the sample reported the following to be "quite a bit" to "very much" important to them: the way in which they perceive their own bodies (40% and 35%, respectively), feeling attractive (35% and 30%, respectively), and the way in which their partner perceives their body (50% and 10%, respectively).

### **Self-Regulatory Strategies**

Using a 5-point Likert-type scale ranging from 1="not at all" to 5="very much", women were asked to rate their ability to manage LE-related thoughts and strategic plans to reduce their risk of developing LE. Overall, women reported a positive sense of control

over their ability to manage LE-related feelings and the behaviors in which they were able to engage. Specifically, the majority of the sample felt that they were "quite a bit" (40%) to "very much" (55%) able to make the necessary lifestyle changes in order to carry out recommended LE minimization precautions and that they were "quite a bit" (35%) to "very much" (45%) able to follow the recommended behaviors that may minimize LE symptoms. A majority of the sample felt that they are "quite a bit" (30%) to "very much" (35%) able to limit the amount of stress they experience when they perform the recommended symptom minimization practices, that they are "quite a bit" (35%) to "very much" (20%) able to limit the amount of stress they experience about their LE risk, and that they are "quite a bit" (25%) to "very much" (25%) able to calm themselves down when they experience anxiety or worry about developing LE.

### CONFERENCE PRESENTATIONS AND DISTINGUISHED VISITORSHIPS

Miller, S.M. 8<sup>th</sup> International Workshop on Infant Cry Research. Speaker on: Maternal coping styles and infant stress. Padova, Italy, August, 2002.

Miller, S.M. Department of Psychology Colloquium in Psychooncology (sponsored by the University of Bologna). August, 2002.

Miller, S.M. Health Psychology Department Colloquium. (sponsored by the University of Rome). Invited speaker on Behavioral Oncology. Orvieto, Italy, August, 2002.

Miller, S.M. Era of Hope Breast Cancer Research Conference (sponsored by the Department of Defense). Invited Keynote Plenary Speaker on: Cutting edges of behavioral research in the prevention of breast cancer. Part of Plenary Session on Breast Cancer Prevention. Orlando, FL, September, 2002.

Miller, S.M. Fox Chase Cancer Center Conference on: Light, Circadian Disruption, and Breast Cancer. Speaker on: Puberty, depression and behavior: Alcohol, tobacco and breast cancer risk. Phila., PA. March, 2003.

Miller, S.M. The Emerging Role of Screening & Prevention in Women's Cancers. (Sponsored by the Lynne Cohen Foundation for Ovarian Cancer Research and the University of Southern California at Los Angeles). Invited speaker on: Psychosocial issues linked to Oophorectomy. Part of Symposium on Intervention Outcomes and Psychosocial Repercussions of Preventive Measures. April, 2003.

Lewis, M., Miller, S.M. Developmental Paths to Sexual Intercourse in Cancer. Paper presented at the 16<sup>th</sup> World Congress of Sexology for the World Association of Sexology. Havana, Cuba. March, 2003.

Miller, S.M. American Cancer Society Board of Directors Meeting. Invited paper presented on: Interventions to reduce cancer behaviors in underserved populations as part

of National Cancer Awareness Week and Pennsylvania Division Initiatives to Address Disparities. Harrisburg, PA. April, 2003.

Miller, S.M. Distinguished Visiting Professor, Department of Psychology, University of Bologna, Italy, May 2003.

Miller, S.M. Invited Colloquium, University of Bologna (Faculty of Psychology), Foundations and Applications of Health Psychology: The Example of Cancer. Bologna, Italy. May, 2003.

Miller, S.M. Invited Colloquium, University of Bologna (Faculty of Psychology), Theory and Research in Cancer: Applications of Genetic Risk. Bologna, Italy. May, 2003.

Miller, S.M. Invited Colloquium, University of Bologna (Faculty of Psychology), Theory and Research in Cancer: Applications to Cancer Screening and Disease Cessation. Bologna, Italy. May, 2003.

Miller, S.M. Invited speaker, Dartmouth University (Norris Cotton Cancer Center). Cancer Control at Fox Chase: Overview of the Program and the Behavioral Research Core Facility. Lebanon, NH. May, 2003.

Miller, S.M. Distinguished Visiting Professor, Japanese Foundation for Aging and Health, University of Mie, Japan, September 2003.

Miller, S.M. 53<sup>rd</sup> Annual Meeting of the American Society of Human Genetics. Paper presented on: Genetic predisposition: Individual evaluations of risk. Part of Invited Session on: Genetic Risk Communication in Theory and Practice: Exploring the Possibilities. Los Angeles, CA. November, 2003.

Miller, S. M. 8<sup>th</sup> International Congress of Behavioral Medicine. Paper on: Tailoring Monitoring vs. blunting in the preparation for stressful medical procedures. Part of Invited Symposium on: Psychological Preparation for Medical Intervention. Mainz, Germany. August, 2004

## CONCLUSIONS

Currently, efforts are underway to bring this study up to date, as outlined in the Statement of Work. As recruitment continues, we anticipate no further obstacles in conducting our study as scheduled, and we expect no major delays in the progress of this project.

Descriptive data collected to this point indicate that there is a need for increased LE education and improved adherence to LE-related behaviors. Although a number of women are aware of LE minimization practices and their potential benefits, preliminary data suggest that they are not incorporating all of the recommendations into their daily lives, especially those that may constitute active strategies. Moreover, our early data suggest that promoting the maintenance of LE preventive/minimization behaviors and

enhancing the management of LE risk-related emotions over time may be a worthwhile focus for a subset of individuals. Taken together, our preliminary findings support the importance of this study in increasing LE-related knowledge and improving health behaviors to reduce women's risk for developing LE.

This research will fill a void in the breast cancer literature with respect to lymphedema. Survivors of breast cancer need to attend to the types of precautionary measures they can employ to prevent and control the occurrence of symptoms. However, little is known about how individuals understand and make sense of these issues, and few resources have been developed to address this problem. Hence, it is important to explore the psychosocial factors that facilitate or undermine the uptake of preventive behaviors, as well as their sustained maintenance over time.

Through more systematic investigation of these factors, we will be able to develop a profile of the role of cognitive-emotional processing in the management of lymphedema. These data will ultimately be used to design and evaluate enhanced management protocols, tailored to the individual's cognitive-emotional signature.

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#### APPENDICES

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